

HUMAN SERVICES BOARD

INTRODUCTION

DISCUSSION

A summary of the facts and procedural history of this matter (much of it noted in the previously issued decisions and recommendations) will help frame the issues. The petitioner is now a seventeen-year-old boy who suffers from Perlizaeus-Merzbacher Disease, a rare and debilitating form of Leukodystrophy. This is a severe disorder of the central nervous system affecting motor control. The petitioner cannot independently sit up, stand, or control his arms and legs. He

uses a custom-made motorized wheelchair to sit up and move about.

The petitioner lives at home with his parents and attends public school. He has always required frequent and often-extensive medical treatment. His constant need for reliable medical transportation is detailed in a letter from his doctor dated December 9, 2005, see *infra*.

Before this appeal was filed, the petitioner's family met virtually all the petitioner's needs for medical transportation by using their own vehicles. For years the family owned a van that was equipped with a special seat and space to carry the petitioner's wheelchair. To access the van the petitioner was transferred from his wheelchair into the van seat, and vice versa when he arrived at his destination. When the petitioner was younger and smaller, another family member (usually his father) would physically pick him up and make this transfer. However, as the petitioner physically grew larger, there came a point where the family could not accomplish this transfer in a safe and effective manner.¹

In late 2004 the family tried using a private transportation provider who could transport the petitioner to medical appointments in a van equipped with a lift mechanism

that allowed him to remain in his wheelchair while getting into, out of, and traveling in the van. Medicaid paid for this service. When reliability problems arose with the provider of this service, the petitioner requested Medicaid coverage for a lift mechanism to install in the family's van so that it could be used without the need to physically transfer the petitioner to another seat in the van.

The petitioner based his request for Medicaid coverage on several sections of the Medicaid regulations, including M108, and on federal and state anti-discrimination provisions. The Department denied this request, and the petitioner appealed.

In his initial Recommendation to the Board to affirm the Department's decision (issued on August 18, 2005) the hearing officer addressed only the petitioner's M108 arguments.² In the Board's initial (August 29, 2005) Order in this matter it was held that, despite compelling medical evidence as to his particular needs, the petitioner had not demonstrated that he had exhausted (or even attempted to exhaust) means to obtain suitable medical transportation as an alternative to Medicaid purchasing a lift to be installed in his family's van. Thus,

¹ The petitioner's transferring needs and requirements are not in dispute.

² This was done primarily to accommodate timeliness issues being urged by the petitioner at that time, and because he felt that M108 was the petitioner's strongest argument.

the Board affirmed the Department's denial of the petitioner's M108 application. At the petitioner's request, however, the Board issued a remand in that Order for the express purpose of "further consideration of the petitioner's *other* legal arguments" (emphasis added) that the hearing officer had not addressed in his prior Recommendation. However, in its Order the Board also advised: "If and when the petitioner can show that using existing transportation services will result in serious detrimental health consequences he is free to reapply for M108 coverage of alternative services, including a wheelchair lift for his family's van."

At a status conference with the parties' attorneys held shortly after the issuance of the Board's August 29, 2005 Order, the hearing officer advised the petitioner that in addition to the "other legal arguments" that the Board would consider on remand, he could also submit further evidence on his M108 request as to the reliability of existing transportation services. This advice was given at the hearing officer's discretion (without objection from the Department) to avoid the petitioner having to file a whole new M108 request if he could obtain the type of additional medical evidence suggested by the Board in its Order, *supra*.

The petitioner did, in fact, submit further medical evidence, which consisted of a letter dated December 9, 2005, from his doctor (see *supra*). In his second Recommendation in the matter, dated March 28, 2006, the hearing officer advised the Board and the parties that he did not consider the doctor's letter to be relevant "as to the actual availability of alternative transportation", which was the M108 issue addressed by the Board in its previous Order. The hearing officer went on to recommend at that time that the petitioner's "other legal arguments" (i.e., the reason for the Board's remand) be "summarily" addressed and rejected.

However, at the Board's meeting on April 19, the parties' oral arguments focused almost entirely on the M108 issue (i.e., the availability of alternative transportation). In its second remand order in this matter (April 21, 2006) the Board, without addressing any other issue, allowed the petitioner the further opportunity to submit "additional evidence as to the availability of suitable medical transportation".

At some point after the Board's second remand of the matter the petitioner informed the hearing officer and the Department that his family had purchased another van and retrofitted it with a lift to accommodate the petitioner's

wheelchair. Since that time, the petitioner's family has resumed furnishing the petitioner with virtually all his transportation. In light of this, the hearing officer encouraged the parties to explore whether the regulations allowed Medicaid payments to be made to his family as the "providers" of medical transportation services for the petitioner.

The parties' positions on this issue, including their factual allegations and legal arguments, are contained in an exchange of letters between themselves and the Board. At this point, it is not clear whether the petitioner is still (either in addition or as an alternative to being approved as a "personal choice driver") seeking reimbursement for his family's costs in purchasing the new van and/or lift mechanism. However, assuming this to be the case, the Board must also consider the sufficiency of the evidence and the legal arguments submitted regarding this issue.

ORDER

The Department's decision not to provide Medicaid coverage for the purchase of a van or van lift is affirmed. The Department's decision to deny Medicaid transportation

coverage for the petitioner's parents as his personal choice drivers is reversed.

REASONS

I. Van Lift

As the hearing officer noted in his Recommendation dated March 28, 2006, at least one of the petitioner's arguments regarding a van lift can be addressed summarily. Inasmuch as there is no claim or showing that a van lift, in and of itself, can be considered "equipment that will arrest, alleviate, or retard a medical condition", it cannot be considered "durable medical equipment" as defined or contemplated in the regulations. W.A.M. § M840.1. Nowhere else in the regulations is a van lift, or any motor vehicle or vehicle modification, identified as a *medical* item or service covered by Medicaid.

Even though a van lift cannot be considered a covered item *per se*, the Department has never disputed that it is required under the regulations to provide the petitioner with *transportation* necessary to meet his medical needs. In this regard, the December 9, 2005 letter from the petitioner's doctor, if nothing else, clearly establishes that the *reliability* of transportation to medical appointments is critically important to the petitioner's health.

The Medicaid regulation regarding transportation services is reproduced below.

Nothing in the plain language of the above regulation can reasonably be read as providing or contemplating the coverage of either private motor vehicles or the purchase of modifications to privately owned vehicles. The petitioner argues that he is only seeking Medicaid payment for a lift, not for a van. However, common sense dictates that if a van lift constitutes a "medical necessity" for him, then certainly the van itself must also. To somehow read the above regulation (or any other Medicaid provision) as requiring coverage of *modifications* to privately owned vehicles, but not the purchase of the vehicles themselves, would create a coverage category for an item that only families who have sufficient means to already own vehicles can possibly use. Such a result would be plainly contrary to the purposes of Medicaid as well as to federal and state constitutional provisions regarding equal protection.

As noted above, there is no dispute that the law requires the Department to provide children who are Medicaid recipients with a "guarantee" of necessary medical transportation.³ The petitioner essentially argues that the evidence in this matter establishes that he has no safe and effective means to access

³ See *Harris v. James*, 896 F.Supp. 1120, 1135 (D.C.Ala. 1995).

medical transportation *except* by using his family's van.

However, any argument he can make regarding the provision of a van lift would, by necessity, also pertain to a van itself, if he (or any other similarly situated recipient) did not already have one. The Board must, therefore, analyze his request for relief accordingly.

The Medicaid program has been in existence nationwide for about forty years, and every state is required by law to provide necessary medical services to eligible children pursuant to the "early and periodic screening, diagnostic, and treatment services" (EPSDT) provisions under 42 U.S.C.A. § 1396d(a),(r)(5). However, the petitioner in this matter has not cited a single instance in this or in any other jurisdiction in which a state Medicaid program has been required to purchase either a motor vehicle or any mechanical modification to a vehicle for any individual recipient of family. While this lack of precedent, in and of itself, does not necessarily resolve the matter, it does compel an extremely careful analysis of the Department's actual legal obligations under the EPSDT program and the ramifications of the petitioner's legal arguments.

If the petitioner is to prevail in this matter, the *ultimate* legal issue that must be addressed is whether

Medicaid must pay for private vehicles or mechanical modifications to those vehicles in cases in which no other suitable medical transportation is available to a recipient.

As noted above, the parties to this matter strenuously disagree over the *facts* regarding the availability of alternative transportation, and over which party has the burden of proof in this regard. At any rate, there is no question that the petitioner in this matter has submitted compelling evidence as to his medical need for reliable transportation and as to the *potential* unreliability of the alternatives suggested so far by the Department.

Unfortunately, however, if it is to be concluded that the Department is *required by law* to buy his family, or any other family similarly situated, a van or a van lift, it must be concluded that the petitioner's burden of proof is significantly greater than the evidence he has submitted thus far.

Obviously, no Medicaid recipient, including the petitioner, ever has a discreet *medical* need for transportation, itself. Transportation is only necessary in order to access needed medical *treatment*. Therefore, any "guarantee" of transportation under EPSDT must be considered

in the context of the necessary medical treatment or service that is being accessed by that transportation.

The evidence submitted thus far establishes that the petitioner's medical needs are singular and extraordinary. But, there is also no question that his need for medical *transportation* is due solely to the fact that he lives with his family. There can be no dispute that the Medicaid program reflects a *preference* for in-home care of children (and, although to a lesser extent, adults as well). But, the issue that this case must ultimately come down to is whether the regulations *require* a state to make in-home care available to all recipients *regardless of their medical conditions*. For the reasons discussed below, it must be concluded that it is only the medical care itself and the access to that care, not the *setting* in which that care is delivered, that is "guaranteed" under the EPSDT regulations.

Unfortunately, there are many children (and adults) who cannot reasonably be expected to live at home and still receive the medical care they need. For this reason, Medicaid specifically covers various levels of institutional care. See W.A.M. §§ M781 & M900. There does not appear to be any dispute in this matter that the petitioner would qualify for institutional care were it not for his family's *wherewithal*

and dedication, which enables him to live at home. To be sure, no one can gainsay this family's choice to keep their child at home. But it cannot be concluded that their decision in this regard establishes or is based on any *entitlement* that flows from the Medicaid program. The petitioner has a right to receive *the same* level of care and benefits allowed for any similarly situated recipient. However, as pointed out in an earlier recommendation in this matter, the Department is not required to provide him with any *special* item or service that *no other* similarly situated recipient receives.

It is a sad, but indisputable, fact that many children, some with medical conditions far less severe than that of the petitioner, must rely on an institutional setting in which to receive necessary medical care. The petitioner in this matter has made no claim or showing that the medical care and services he needs would not be available to him in an institutional setting. Actually, the argument he needs to make to prevail in this matter is the opposite; i.e., that if he does not have a van lift (or a van) he cannot access necessary medical care from his home—and that this would *force* him to be institutionalized.

As noted above, there does not appear to be any dispute that the petitioner *could* receive all necessary medical care

in or under the auspices of an institutional care facility, and that he would qualify for such care if his family was no longer able or willing to access this care from their home. Because of this, it cannot be concluded that the Department is "discriminating" against the petitioner if it does not purchase his family a van or van lift so he can access those services from his home. To conclude otherwise would require the Department to provide virtually any medical service, at any cost, which would keep every child out of an institution. Although such a result may be entirely defensible as a matter of enlightened social policy, there is no indication or precedent that it is mandated by the Medicaid program as it presently exists.

The above analysis begs the question, however, of whether payment for a van or van modifications is allowable under the Department's M108 regulation. As noted above, despite the submission of additional evidence, the parties remain in marked disagreement whether the petitioner's reliance on existing transportation services will result in "serious detrimental health consequences".⁴ However, similar to the

⁴ Inasmuch as the Board's prior decision regarding M108 was made before the receipt of substantial additional evidence, that decision cannot be considered *res judicata*.

above analysis regarding EPSDT, the *ultimate* issue under M108 that will have to be addressed is whether it is an abuse of discretion for the Department to deny Medicaid coverage for the purchase of any non-medical item, *including* private vehicles and modifications to those vehicles, in cases where institutionalization will result if such coverage is not provided.

As noted above, this is not to say that the petitioner in this case has made such an evidentiary showing. Indeed, there is no indication that any of his medical providers, much less the Department, has even *considered* his request for a van lift in this light. In light of the potentially huge policy and monetary implications of expanding M108 to include such coverage, and considering that M108 coverage (unlike the EPSDT provisions, discussed above and below) is largely discretionary, it would be inappropriate for the Board to consider this issue in advance of the petitioner conclusively establishing that such a choice (a family-owned van versus institutionalization) is clearly and unavoidably presented by the facts in this matter.

II. Personal Choice Driver

As a legal matter, the petitioner's request that his parents be covered as Medicaid transportation providers as his

"personal choice driver" is a horse of an entirely different color. In the parties' correspondence (see *supra*) the Department took the following position:

"The Medicaid transportation program is structured so as to provide alternatives to brokered public transportation services, if those services for one reason or another are deemed unacceptable. Medicaid will pay for qualifying transportation to and from necessary medical services that is provided by a "personal choice driver." Such services are subject to the same prior authorization and other eligibility requirements as rides obtained through a broker, with the difference that the recipient identifies and arranges for his or her chosen driver without going through the broker as an intermediary. It is likely that your client could find a person or service with a wheelchair-equipped van in his area who would be willing to serve as a "personal choice driver."⁵

Subsequent correspondence makes clear, however, that the above "offer" of a personal choice driver by the Department was based on its assumption at that time that the petitioner was no longer able to use his family's van due to the absence of a lift; i.e., before the Department understood that the petitioner's family had already purchased a different van and had installed a lift in it. Thus, when the petitioner indicated that he was seeking Medicaid transportation coverage for a personal choice driver, it was for *his parents* as

⁵ June 8, 2006 letter from Atty. Steinzor to Atty. Prine.

drivers of the lift-equipped van that the family already owned.

The Department later made clear that it was denying this request based on its reading of paragraph 2 of M755, *supra*, limiting Medicaid coverage for transportation to situations where "transportation is not otherwise available to the Medicaid recipient". According to the Department, its "policy" is to deny coverage for any Medicaid transportation "if the family owns an adequately equipped vehicle for transporting a disabled family member".⁶ In terms of coverage for medical transportation, it appears that the Department, despite the petitioner's admittedly extraordinary transportation needs, views his situation as essentially no different from that of any child who is driven by his parents to doctor's appointments in the family car.⁷ It is concluded that this is an overly restrictive reading of M755 and does not meet the requirements of EPSDT (see *supra*), which "ensures that every eligible recipient receives necessary

⁶ October 5, 2006 letter from Atty. Steinzor to hearing officer.

⁷ The Department represents that, in some cases, a "hardship mileage reimbursement" might be available to the family, for which the Department has invited the petitioner to apply. However, the petitioner's potential eligibility for mileage reimbursement does not appear to be an issue at this time.

transportation to and from the doctor and other medical providers".⁸

The issue of whether the regulations require the Department to provide coverage for the petitioner's parents as personal choice drivers of their family's van is far different than whether the Department is required to purchase the van in the first place. There is no dispute that, as a general matter, personal choice drivers, unlike vehicle purchases, are *already covered* under M755. The Department has not taken any issue with the petitioner's allegation that there are no other personal care drivers in their service area.⁹ The sole reason given by the Department for its denial of coverage in this case is that it is the family, rather than another party, who owns the van that is used to transport the petitioner.

There is no dispute that if (as the Department originally thought) the petitioner's parents did not own a van sufficiently equipped to carry the petitioner, they would be approved under § M755 to hire another person with a suitable van to drive him to his medical appointments, and that Medicaid would pay that person its prevailing rate to provide that service. The only difference in what the petitioner is

⁸ See *Harris v. James*, Id.

⁹ See July 31, 2006 letter from Atty. Prine to Atty. Steinzor.

now seeking is to have Medicaid pay his parents, rather than another party, *the same prevailing rate to use their own van to provide the exact same service*. It must be concluded that the Department's refusal to do so is based on a distinction without a rational difference as a matter of either law or policy.

In light of the fact that the Department has clearly conceded that the petitioner's medical needs are such that he could obtain Medicaid coverage for *another person* to be his personal choice driver, it must be concluded that the criterion in § M755 that transportation is "not otherwise available" has been met. The Department has not pointed to anything in § M755 or anywhere else in the regulations that precludes family members *per se* from being Medicaid transportation providers. Even if the Department would contest whether other suitable personal choice drivers are available, it makes no sense as a matter of either law or policy to require a recipient whose family already owns a suitable vehicle to hire a third party to provide transportation, rather than simply reimburse a family who can provide the exact same service with indisputably greater convenience and reliability.

Thus, based on the facts regarding the petitioner's circumstances that it has either already conceded or not contested, it must be concluded that the Department, in order to meet the requirements of EPSDT, must provide Medicaid transportation coverage under § M755 for the petitioner's parents as personal choice drivers at the same rate and under the circumstances that it would have covered another individual or company to perform this service.

#